



PERSONS WITH INDEPENDENT EMPLOYMENT SERVICES QUALITY OF LIFE DISABILITIES

"Empowerment is not empty rhetoric. It is the difference between dictatorship and democracy. It is the difference between paternalism and freedom. It is the difference between partial prosperity for the few and full prosperity for all."

– Justin Dart, Jr., 1999

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PERSONS WITH DISABILITIES

How is this parish doing?

Persons with disabilities ☹️

Physical disabilities ☹️

Children's Special Health Services 😊

Causes of disability ☹️

DID YOU KNOW?

Under the Americans for Disabilities Act (ADA), a person with a disability is someone with a physical or mental impairment that substantially limits one or more activity of daily living (ADL), or someone with a record of such an impairment or who is regarded as having such an impairment. Talking, walking, seeing, hearing, grooming, dressing/undressing, moving in and out of bed, and meal preparation are examples of activities of daily living.

- Council of Better Business Bureau's Foundation, 1992.

DISABILITY

The U.S. Census Bureau estimated in 1997 that close to one in five Americans have some kind of disability, and one in ten have a disability that is severe. The number of persons with disabilities will increase in coming decades as the number of people over age 65 increases. Improvements in medical technology will also allow more people to live with disabling conditions ([1] U.S. Census, 1999). People living with any disability will experience greater medical costs and have more problems with access to care than people without a disability. They will also have more obstacles in their daily living (McNeil, 1997 and [1] U.S. Department of Health and Human Services, 1998).

The subject of disability has been touched upon in other sections of this book in terms of prevention. A few examples of ways to prevent disability that were mentioned in other sections are:

- Using seat belts, helmets and child car seats;
- Eating healthy diets rich in folic acid as preparation for pregnancy; and
- The importance of iron-rich foods to developing children.

This prevention advice is important to remember and promote in communities. It is equally important to create opportunities for persons with disabilities to live in and contribute to community life. This chapter discusses people who are affected by disability and considers ways for communities to support a full life for them. The first section of the chapter looks at who is disabled in a community and then at the appropriate services for persons with disabilities. Because many disabilities can be avoided, there is a discussion about preventable injury, the most common cause of disability. Finally, there is a section about the elderly and their quality of life, including disability.

This following indicators are in this section:

- People living with disability
- Prevalence of disability
- Rates of traumatic brain injury
- Causes of TBI and SCI
- Enrollment in Children's Special Health Services
- Disability and employment
- Social security payments by diagnosis
- Rates of spinal cord injury
- Elderly population
- Elderly in poverty
- Elderly living situations

There are many kinds of disabilities. Some disabilities are visible, such as spinal cord injuries and some physical birth defects. Others are not so easy to see. The burden of heart disease, deafness or diabetic complications may not be apparent to casual observers. Some people are born with disabilities, others develop them from injury or illness. Sometimes disabilities simply result from becoming frail with age.

Figure 1 presents the data from the most recent U.S. Census report on percent of disability. The U.S. Census Bureau used data models to estimate that 24.5 percent (46 million) of persons 16 years old and older in the U.S. had some disability in 1990 (U.S. Census, 1997 and (2) U.S. Department of Health and Human Services, 1998). In Louisiana 30.2 percent (913,041) of people 16 years old and older had a disability of some kind. **In Tensas the estimate was 38.5 percent (1,930)** ([1] U.S. Census,

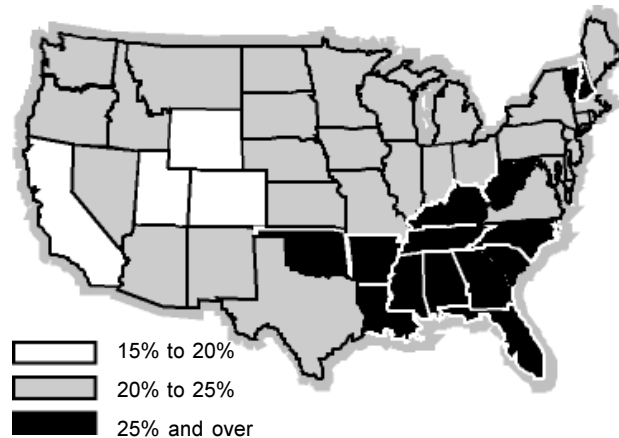


1996). Additionally, 10.4 percent of non-institutionalized civilians in the U.S. aged 16 to 64 had a disability that prevented them from working. In Louisiana the estimate was 5.9 percent or 149,556 people. **In Tensas it was 7.1 percent (273)** ([2] U.S. Census, 1996).

The data that is collected about disabilities is often

about the people who are using services, such as disability claims or reported occupational injuries. There are people with disabilities who are not part of those service data sets. The number of disabled, mentally ill and elderly in an area is often under-reported. Those populations are usually less visible. They may not show up in service statistics because the family may try to care for them unaided. Often they have mobility problems and are less able to be active in the community. Active collection of information will help communities understand issues and improve the quality of life of people with disabilities. The best way to know what is going on is to talk to people with disabilities, and include them and their families in the community planning.

Figure 1:
Percentage of People with Any Disability of 16-64 population,
by State, 1990



Sources: U.S. Census Bureau, Census Disability Data, 1999

DID YOU KNOW?

Some people with disabilities are:

- Former President Franklin D. Roosevelt, polio;
- Actress Mary Matlin, deaf;
- Actor and writer Christopher Reeves, spinal cord injury - quadriplegia;
- Senator Max Cleland, U.S. Senator, D-GA, multiple amputee;
- Senator John Kerry D-KS, amputee; and
- Former Senator Robert Dole, ex-presidential candidate, paralysis.

Taking Care, Taking Control: WRBH-FM, 88.9, Radio for the Blind

We all know that some of the best radio stations in the world are here in Louisiana. But did you know that one of our most innovative stations doesn't even play music? WRBH 88.9-FM "Radio for the Blind" is one of a very small number of radio stations in the world that provides 24-hour programming for the blind and visually impaired. WRBH was started by a blind math professor at Loyola University in 1982, Robert McLean. His dream was to provide access to mainstream print media and literature to people who were visually impaired, since most of the blind couldn't afford to pay someone to read to them.

From a humble beginning of a few hours borrowed from UNO's radio station, WRBH has grown into 24 hour

programming, with a strong FM signal and, now, the station is in its own building.

In the new building in New Orleans, the station has also become a community center for the blind. There are classes to teach job skills, resume writing, interviewing tips and reading Braille. The local chapter of the National Federation of the Blind and the Blind Veterans of America hold their monthly meetings at the station, too.

Some things haven't changed, though. Readers are all volunteers. And like many volunteer organizations, theirs is a small staff with big dreams for the future.

- For further information: Randy Savoie, Station Manager and Program Director, WRBH-FM, 88.9 3606 Magazine St., New Orleans 504-899-1144

**taking
care
control**
**Opening
the ears
to the
world:
An
innovative radio
station
for the
blind**



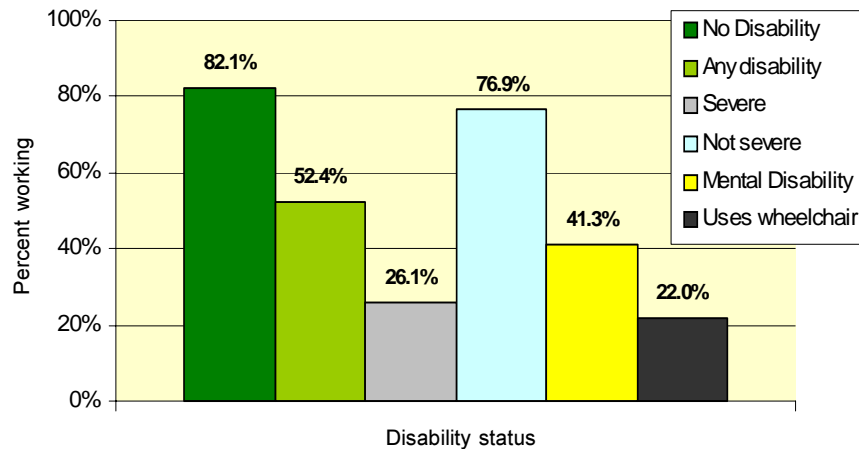
PERSONS WITH DISABILITIES

DID YOU KNOW?

The cost of accommodating an employee with a disability is low - typically between \$50 and \$200. About 17% of accommodations require no expenditure at all. Simple tricks like a portable ramp, or using bricks to raise the height of a desk to fit a wheelchair can make an office accessible.

- (2) Kaye, 1997.

Figure 2:
Employment status of persons 21-64,
United States, 1994-95



Source: (2) U.S. Bureau of Census, 1999.

Community members will need to collect more local information about efforts to remove the barriers for people with disabilities. Counting the number of buildings with ramps or elevators is a good information tool. Other examples of useful indicators of accessibility is the location and number of disabled parking spaces or transportation systems that are disability accessible. Examining local businesses' capacities for hiring the disabled is another valuable indicator. Community members share in the benefits of creating a disability friendly environment. For example, wheelchair-accessible buildings and mechanically lowered bus steps are also useful to the elderly and people with child strollers.

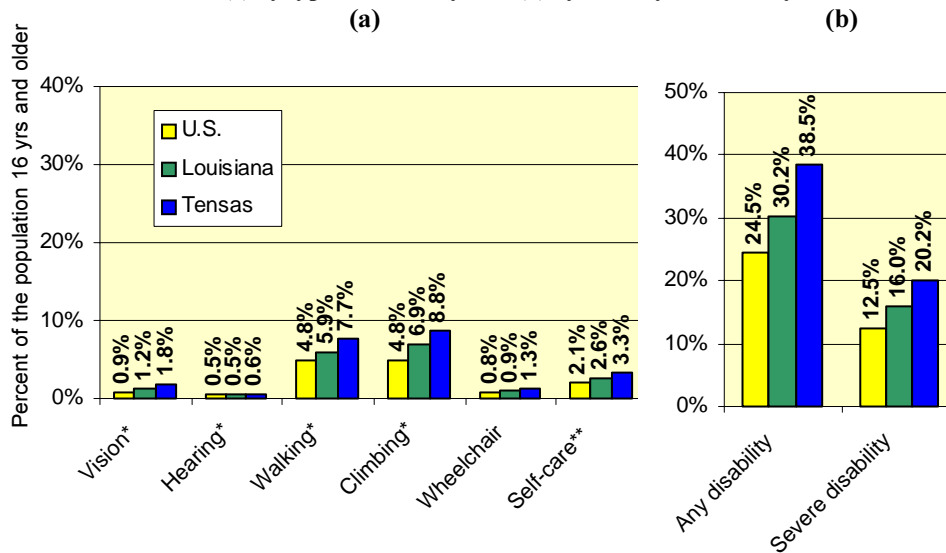
WORKING WITH A DISABILITY

Physical limitations create great obstacles for individuals. People with a physical disability are less likely to find appropriate work. Only 22 percent of persons using a wheelchair, 21 to 64 years of age, are employed. This is compared to 80.5 percent of the non-disabled ([1] Kaye, 1997). It can be hard for persons with physical disabilities to make ends meet and obtain needed care. It may also be hard to function in an environment built for able-bodied persons. Persons with disabilities often face fear, uncertainty and rejection from people who do not know how to behave with them because they look, move or act differently.

Many persons who have disabilities are not working, as shown in Figure 2. No one knows how many could or would work with appropriate care and access. Care systems have not been able to keep up with the wide range of life situations that arise for people with disabilities. Some of the problems are with the rigid criteria for qualifying for services. These criteria were first put into effect to prevent fraud and to target services correctly.



Figure 3:
Prevalence of Disabilities Using Model-Based Estimates, Persons Aged 16 and Older,
United States, Louisiana and Tensas Parish, 1998
(a) by type of disability, and (b) by severity of disability



* inability to: see words in newspaper, hear an average speaking voice, walk three blocks, climb stairs

** have difficulty with self care activities

Source: (1) U.S. Census Bureau, 1996 and (1) Social Security Administration, 1998

There can be drawbacks for joining or returning to the work force. People who receive disability benefits may lose them if they earn even modest amounts of income. There are a number of reasons that people receive disability benefits (see Figures 3 and 4). A system has to be flexible to fit so many kinds of needs. In one federal program, the title home bound, can be removed from a person with a disability who leaves their home for shopping or other nonmedical errands on a routine basis. When they are no longer home bound they can lose benefits for services, such as their personal attendants (PAs). For some persons with disabilities, the quality of their lives depends on the prescriptions, technology, medical care and PA services that they

Taking Care, Taking Control: Community living for persons with disabilities

Twenty to thirty years ago, people born with severe handicaps and mental disabilities were oftentimes confined to state-supported institutions. These services were sought because Medicaid only paid for this expensive care within an institutional setting. Today, times have changed, and more and more parents seek to have their children with disabilities live a normal life in a community setting. Steve's story is an example of this changing philosophy.

Now in his mid-30's, Steve is the sixth of seven children. He is no different from his brothers and sisters, except that he has an additional quality. Steve is autistic. His parents

have always believed that he would be as independent as he could be by the time he was 30 years old. He is meeting these goals.

Steve was in the first classroom for autistic students on a regular elementary school campus. He was also in the first classes of "mainstreaming" on junior and senior high campuses. He was the first autistic person in supported employment in Louisiana. In addition, he lives in his own apartment under a Medicaid MR/DD Home and Community Based Waiver.

- For further information: Robert Johannessen, Director of Communications, Louisiana Department of Health and Hospitals, 225-342-6039.

**Options
for
persons
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living
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**PERSONS WITH
DISABILITIES**

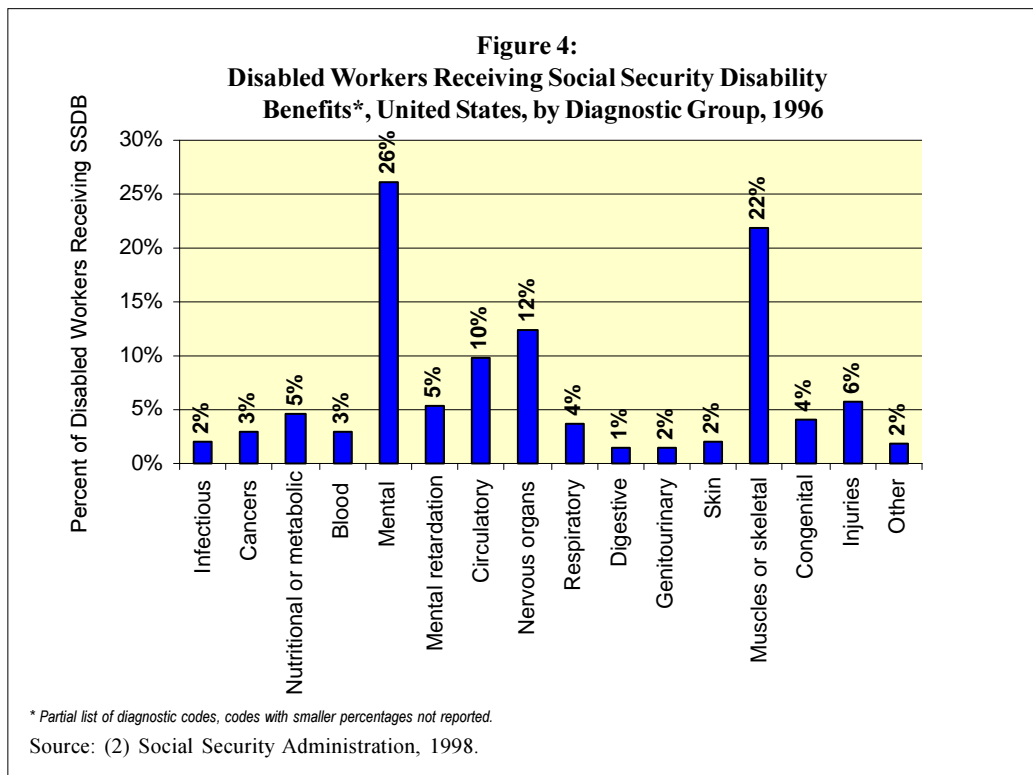
DID YOU KNOW?

In 1995-96, 18,027 persons with disabilities were served by Louisiana Rehabilitation Services (LRS). Of the eligible clients who were served, 2,953 were successfully rehabilitated and a little over 15,000 continued to receive services.

- Louisiana Rehabilitation Services, 1997.

The LRS Community Rehabilitation Program offers employment assessment, planning and development of work-related skills and behavior through a program called Rehabilitation Employment Assessment Program (REAP).

- Louisiana Rehabilitation Services, 1997.



receive. Along with state and federal programs, community-based organizations, such as centers for independent living (CIL), that are dedicated to keeping persons independent. There are over 300 CILs nationwide, and three in Louisiana. CILs came out of the disability rights movement which successfully lobbied for the Americans with Disabilities Act of 1990 (ADA).

The Louisiana Department of Health and Hospitals Office for Citizens with Developmental Disorders (OCDD) is also working to make it possible for persons with

disabilities to live and work independently in community. Through the Medicaid MR/DD Home and Community Based Waiver program, individuals across the state are able to work in supported employment and live in their own apartments. In January 1991, there were only 1,900 people receiving these services. OCDD estimates that number will be up to 4,000 by June 2000. This program has been recognized by the Health Care Financing Administration as a national example of good programming (Department of Health and Hospitals, 2000).

Services

Federal, state and local agencies along with community-based organizations use data

“...for every dollar spent on vocational rehabilitation, the rehabilitated clients generate over \$25 in personal, taxable income...”



to design and provide services for those with disabilities. Services include housing, transportation and in-home PA care. Investments in vocational rehabilitation, training and enabling technologies have been important to improve independence and quality of life. Two important enabling technologies are voice recognition software on computers and advances in wheelchair design. Investing in technologies, employment and services to keep people independent is sound economic decision-making. In a cost benefit analysis conducted by the Virginia Rehabilitation Center, researchers found that for every dollar spent on vocational rehabilitation, clients generate over \$25 in personal, taxable income. In 1993, the Internal Revenue Service estimated the average rehabilitated client repays the cost of services at least nine times over. This happens when the person with a disability who is working pays taxes and has a decreased need for public assistance (LaPlante, 1996). Computers and assistive technology have made a wide range of occupations possible for persons with disabilities.

Financial access to services

A lack of health insurance greatly impedes access to health care. This is a significant problem for people with disabilities, who often have high, ongoing demand for health services. Persons with disabilities may lack health insurance because they have been denied coverage for preexisting conditions. They may also face high premiums and restricted eligibility for public insurance (Children's Special Health Services, 1998).

On average, persons with disabilities spend more than four times as much on medical care, services and equipment as their non-disabled counterparts. While persons with disabilities make up between ten and 20 percent of the non-institutionalized population, they account for 47 percent of medical expenditures. These individuals see a physician an average of 14 times per year. Persons with disabilities who lack health insurance coverage utilize health care services much less frequently than those who do have insurance (Children's Special Health Services, 1998).

Among persons with disabilities, having insurance is significantly associated with more physician contacts. Not having insurance generally lowers utilization for all groups, but for the uninsured with severe disabilities, this may force them to forgo physician services that are necessary to maintain their health (Children's Special Health Services, 1998).

CHILDREN'S SPECIAL HEALTH SERVICES

Children's Special Health Services (CSHS) serves as the principal public agency ensuring that children with special health care needs in this state have access to health care services. These services are designed to help them live an independent life. CSHS acts as a direct service provider, a case manager or an assistant in managing finances to assure that quality health care services are provided to children with special health care needs. CSHS works in partnership with other federal, state

DID YOU KNOW?

"The presence of a disability is associated with lower levels of income and an increased likelihood of being in poverty."

- McNeil, 1997.

As of October 1997, there were 93,936 students with disabilities, three to 21 years of age, in Louisiana schools.

- Louisiana Network of Special Education Records (LANSER), 1997.

A developmental disability is a severe, chronic disability of a person which:

- *is a mental and/or physical impairment;*
- *manifests before 22 years of age;*
- *is likely to continue indefinitely;*
- *results in functional limitations in self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and/or economic independence; and*
- *reflects the person's need for special, interdisciplinary care, treatment or services.*

- Office of Citizens with Developmental Disabilities, 1999.



PERSONS WITH DISABILITIES

DID YOU KNOW?

Nationally, about 1.2% of the population experiences a developmental disability (see definition on previous page side bar).

- Office of Citizens with Developmental Disabilities, 1999.

and local programs. In addition it works with public and private agencies, institutions and providers. Together the partnership works to meet the changing demands of families and children with special health care needs (Children's Special Health Services, 1998).

The number of children enrolled in the Louisiana CSHS program in 1997 was 12,570. According to the 1990 U.S. Census, 29.1 percent of Louisianians under age 18 have a disability. This is the 6th highest state population with a disability in the nation (Children's Special Health Services, 1998).

In 1996, 38,590 children with disabilities in Louisiana received Supplemental Security Income (SSI) benefits. Persons with disabilities use more medical services compared to those without disabilities. The high number of disabilities among children in Louisiana suggests an additional need for health care services and resources.

The Federal Maternal and Child Health Bureau defines children with special health care needs as:

Children with special health care needs are those who have, or are at increased risk for, a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (Children's Special Health Services, 1998).

“... 29.1 percent of Louisianians under age 18 have a disability. This is the 6th highest state population with a disability in the nation.”

Taking Care, Taking Control: Advocating for Better Schooling

**Opening
the
class-
rooms:
Advocat-
ing for
children
with
disabili-
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Virginia describes herself as “just a parent.” But sometimes parents are called upon to do extraordinary things.

In Virginia's case, she and another friend took on a whole parish school system in order to start the first class for students with autism in her parish.

Virginia swears she didn't do anything that any other parent wouldn't have done. But how many parents have to convince a whole school system that it has the responsibility to educate their seven year-old? In order to do this, Virginia and her friend had to recruit independent, nonprofit and state assistance for technical information to help provide disability education in the schools. They located classes for students with autism in

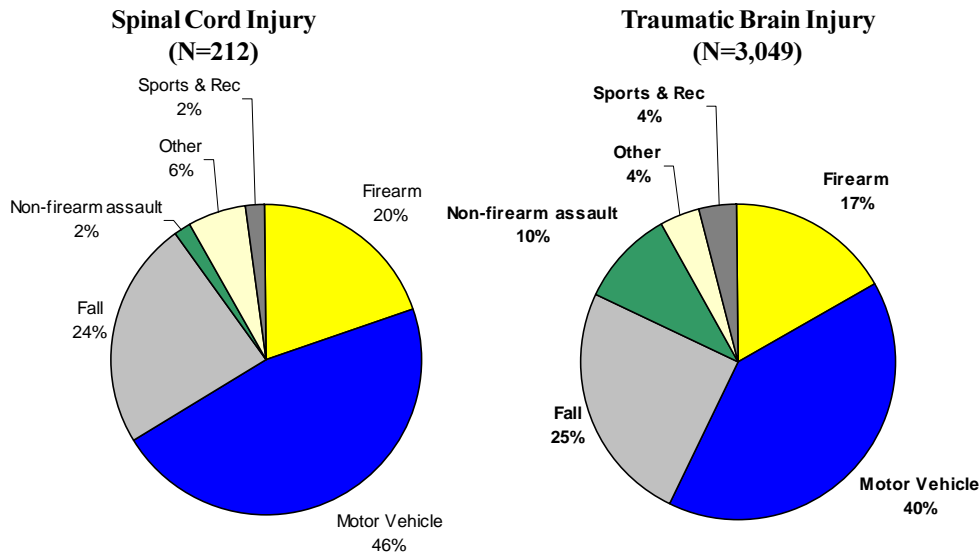
neighboring school systems and convinced their parish school board to observe these classes. They also sought out school personnel who were trained and available to teach and create an appropriate individual program for Virginia's child.

Virginia and her friend did all these things. In addition, she wrote letters, attended numerous school board meetings and became a “self-taught” advocate for the rights of children with disabilities. Not only did her hard work help her own child, who is now in school, but it has paved the way for other children with disabilities to participate in schools as equal citizens.

- For further information: The Advocacy Center, 225 Baronne Street, Suite 2112, New Orleans, LA 70112 800-960-7705 (voice/TDD)



Figure 5:
Causes of Spinal Cord Injury and Traumatic Brain Injury,
Louisiana, 1996



Source: Injury Research and Prevention Program, 1998.

DID YOU KNOW?

"As of June 1997, there were approximately 9,864 persons on the waiting list for the Home and Community Based MR/DD Waiver for services. Some of those persons from DHH Administrative Regions 3, 4, and 8 have been waiting for services since 1992."

- (3) The Office for Citizens with Developmental Disabilities, 1997.

Federal estimates are that 18 percent of children in the United States below the age of 18 fit the Federal Maternal and Child Health Bureau's definition (Children's Special Health Services, 1998). Estimates based on that percentage indicate over 200,000 children in Louisiana have special health care needs.

Preventable injuries

Preventable injuries, along with chronic disease, are leading causes of death in Louisiana. They are also a major cause of disability. Injuries are not true accidents, as they are commonly called. The term "accidents" implies a chance event, out of a person's control. Injuries are often preventable and even foreseeable. If those foreseeable injuries are prevented, then some disabilities can be prevented (Injury Research and Prevention, 1998).

Injury to the brain and spine causes damage to the central nervous system. This kind of damage can interfere with vision, motion, thought processes and even personality. Certain types of injuries may result in short or long term comas.

Mild Traumatic Brain Injury

A blow or jolt to the head can cause a type of mild brain injury called a concussion. Some symptoms of a concussion are:

- Persistent low-grade headaches;
- Having more trouble than usual remembering things, concentrating, or making decisions;
- Feeling tired all the time;
- Feeling sad, anxious, or listless; and/or
- Becoming easily irritated for little or no reason.

- Source: Centers for Disease Control, 1999.

Method of Payment for Traumatic Brain Injury

Private insurance	32%
Government	30%
Uncompensated	29%
Liability	6%
Workers compensation	3%

Source: Injury Research and Prevention Program, 1998.



**PERSONS WITH
DISABILITIES**

DID YOU KNOW?:

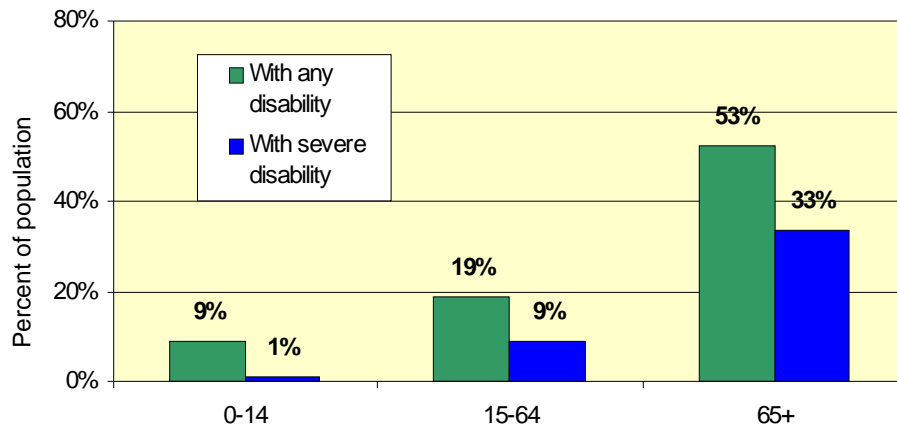
Between 1970 and 1997, the percentage of elderly who had completed high school rose from 28 to 66%. About 15 percent in 1997 had obtained a bachelor's degree or higher.

- (3) Administration on Aging, 1998.

In 1995, 28.3% of the elderly assessed their health as fair to poor compared to 9.4% for all persons. African American elderly were much more likely to rate their health as fair or poor (43 %) than were white (28 %).

- (3) Administration on Aging, 1998.

**Figure 6:
Persons with Disabilities, by Age,
United States 1994-95**



Source: (3) Administration on Aging, 1998.

Brain injury can occur in many ways. Traumatic brain injuries often result from accidents in which the head strikes an object. Injuries that involve motor vehicles, falls and guns cause the largest portion of TBI in Louisiana (see Figure 5).

In Louisiana in 1996, traumatic brain injuries occurred at a rate of 92 per 100,000 people. Seven out of 100,000 had spinal cord injuries. The rates for men in both types of injury were nearly 2.5 times the rates for women. Alcohol was involved in 16 percent of the traumatic brain injury events. Illegal drugs were involved in eight percent. Alcohol and drug use increase the chances of all types of injury (Injury Research and Prevention, 1998).

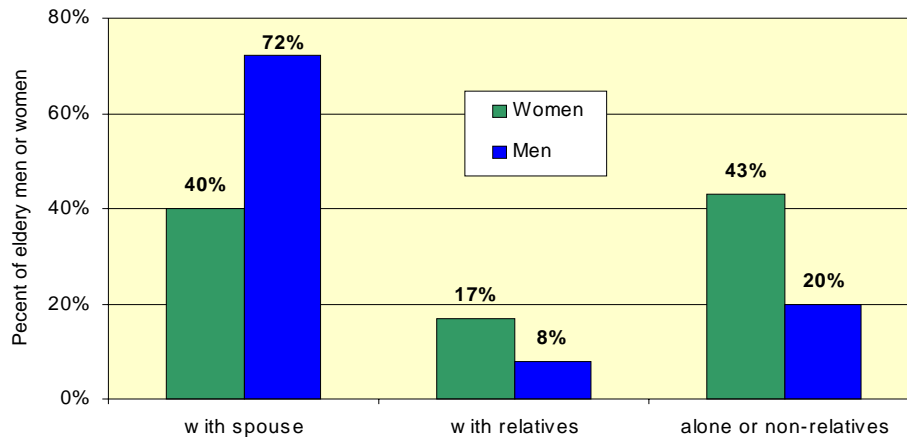
Widespread injury prevention often requires changes in policy and enforcement in public laws that address safety in public situations. For example, car safety includes not driving while intoxicated and wearing seat belts at all times. Using other motor vehicles, such as bicycles and motorcycles, will be safer if helmets are worn. A rider without a helmet is 40 percent more likely to suffer a fatal head injury, compared to a helmeted rider ([3] U.S. Department of Health and Human Services, 1998).

Elderly

Another cause of disability is increased frailty brought on by aging. Bones can break more easily and chronic diseases can limit mobility, sight, hearing or clarity of thought. The population of elderly is growing in Louisiana. **In Louisiana in 1997, there were 469,789 persons age 65 and older. They make up 11.4 percent of the state's population. Nearly one in five elderly people in Louisiana live in poverty** (State of Louisiana Governor's Office on Elderly Affairs, 1998). The population of elderly is predicted to nearly double by the year 2020 ([1] Administration on Aging, 1998).



**Figure 7:
Living Arrangements of Persons over 65 years old,
United States, 1996**



Source: (3) Administration on Aging, 1998.

DID YOU KNOW?

About 8% of people over age 70 visit emergency departments each year for injuries caused by a fall, and 30 to 40% are admitted to the hospital. As much as 50% of those falls might be avoided by a comprehensive medical assessment of sight, balance, blood pressure, medications and a household evaluation of risks.

- Close, 1999.

People in Louisiana are living longer lives. Productive years of life are increasing. Seniors are playing vital roles in all areas of the community. Their knowledge, experience and understanding of community history and tradition are a great resource. Nationally, about 12 percent of older Americans are in the work force. They make up almost three percent of the U.S. labor force. In addition, seniors' contributions of volunteer hours and money have long been vital and important to communities ([2] Administration on Aging, 1998).

“In 1995, over one-third of the elderly reported they were limited by chronic conditions.”

Along with these special skills and abilities come special needs. Health, economic and social needs increase with age. The number of those living well into their eighties and nineties is increasing. Those over age 85 only made up 1.4 percent of the national population in 1995 ([1] Administration on Aging, 1998). However, as the baby boomers reach this age between 2030 and 2050, the proportion

of seniors is expected to reach nearly five percent. It will be necessary to increase the services provided to this population, including housing, transportation, recreation, education and health care ([1] Administration on Aging, 1998).

Where, and under what conditions, the elderly live has a great impact on their quality of life. A family can provide a supporting and caring atmosphere. Eighty percent of older males and 57 percent of older females live in family settings. Often the elderly must live outside the home in order to get continuous care. Nationally, four percent of

**PERSONS WITH
DISABILITIES**

the people age 65 and older live in nursing homes. Fifteen percent of people over age 85 live in nursing homes ([2] Administration on Aging, 1998).

Difficulties arise when there is not enough time and money to care for older loved ones. Families and even communities must weigh the options of home health care, adult centers of care and nursing homes.

In 1995, over one-third of the elderly reported they were limited by chronic conditions. Arthritis, hypertension, heart disease, hearing impairments, cataracts, orthopedic impairments, sinusitis and diabetes are the most frequent conditions ([2] Administration on Aging, 1998). Chronic disease also has an enormous impact on the health care system. Older people account for nearly 40 percent of all hospital stays. They account for 49 percent of all days of care in hospitals nationally ([2] Administration on Aging, 1998). Disabilities are much more common in the elderly. More than half of the U.S. population over 65 reported having at least one disability. One-third had severe disabilities (see Figure 6).

Poverty can be especially hard on the elderly. **Over the period of 1994-96 almost 18 percent of the elderly in Louisiana were living in poverty.** This is one of the highest levels in the country ([1] Administration on Aging, 1998). For women, minorities and those living alone, this rate is even higher ([2] Administration on Aging, 1998). Poverty impacts health and well-being and is related to increased disability. Seventy-one percent of low-income elderly experience a disability. Forty-eight percent of the overall elderly population have a disability. It is estimated that the number of elderly with disabilities in the U.S. will grow to around 10 million by the year 2020 ([2] Administration on Aging, 1998).

THE COMMUNITY CAN . . .

To increase the capacity for caring for people with disabilities, chronic mental illness and the elderly, individuals, families and communities can:

- Keep the elderly or persons with disabilities at home instead of in institutions. Promote nonmedical care to keep people independent.
- Invest in respite care or adult centers of care. This will allow families to keep their elderly or disabled at home.
- Create changes in the community which will assist in accessing transportation, buildings, community events, etc. This, in turn, assists all members of the community with disabilities.
- Create help groups which provide coping skills and support for those caring for elderly loved ones or persons with disabilities.
- Contribute coaching, job-training and services to programs which help youth with disabilities move from school to the working world.



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